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Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Rights of persons with disabilities

Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar, submitted in accordance with Human Rights Council resolution 35/6.

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Report of the Special Rapporteur on the rights of persons with disabilities

Summary

In the report, the Special Rapporteur on the rights of persons with disabilities examines the challenges experienced by persons with disabilities in the enjoyment of their right to the highest attainable standard of health, and provides guidance to States on how to promote health-care services that are inclusive of, and accessible to, persons with disabilities.

I. Introduction

1. The present report underscores the various challenges faced by persons with disabilities to the enjoyment of their right to the highest attainable standard of health, and provides guidance to States on how to promote human rights-based health-care services that are inclusive and accessible. The international human rights standards presented in the report build on previous recommendations by the United Nations human rights mechanisms, including treaty bodies and special procedures.

2. In preparing her report, the Special Rapporteur analysed 116 responses to a questionnaire sent to Member States, national human rights institutions and civil society organizations, including organizations representing persons with disabilities.[1] She also organized an expert consultation with representatives of United Nations agencies, organizations of persons with disabilities and academics.

II. Understanding the health of persons with disabilities

3. Health is central to well-being and human happiness. It enables individuals to have a good life and reach their full potential. When people do not have access to health care, including medical and rehabilitation services, they may be unable to attend school, access livelihood opportunities or participate in society. Health is essential to economic growth, as healthy populations study more, are more productive, save more and live longer.[2] Early access to health and rehabilitation services ensures better health outcomes and reduces the costs incurred by health and social care systems associated with poor health. Health goes beyond formal health-care systems. Factors such as safe and affordable housing, transportation, education and employment also have an impact on the health of individuals and communities. Accordingly, health is both an outcome of and a path to achieving sustainable development (see A/71/304).

4. Persons with disabilities have the same health needs as everybody else, including the need for health promotion, preventive care, diagnosis, treatment and rehabilitation. They may also have additional specific health needs resulting from their impairments and other underlying determinants of health, such as poverty, discrimination, violence and social exclusion. While some impairments inevitably progress over time, poor physical and social environments can aggravate primary conditions or exacerbate secondary consequences of primary conditions.

5. Owing to high levels of poverty, discrimination, violence and social exclusion, as well as significant barriers in access to health-care services, persons with disabilities are at higher risk of developing ill-health than the general population and, therefore, more likely to require and use health-care services. For example, they are at higher risk of unintentional injury; developing secondary, co-morbid and age-related conditions; being exposed to violence; and premature death.[3] Likewise, they are in greater need of health-related habilitation and rehabilitation services, which are key to maintain a good health state, live independently, be economically productive, and live meaningful lives. Some persons with disabilities might need more access to specialist health-care services, in addition to primary health-care services.

[1] See www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/StandardOHealth.aspx.

[2] See D. Bloom and D. Canning, *Population Health and Economic Growth* (Commission on Growth and Development, 2008). Available at https://siteresources.worldbank.org/EXTPREMNET/Resources/489960-1338997241035/Growth_Commission_Working_Paper_24_Population_Health_Economic_Growth.pdf.

[3] World Health Organization (WHO) and World Bank, *World Report on Disability* (2011), pp. 53–60.

6. Persons with disabilities can lead active, productive, long and healthy lives. Having an impairment does not equate to being unhealthy. Health is a dynamic state of well-being resulting from a combination of an individual's potentials, life's demands and social and environmental determinants.[4] Regardless of the impairment or health condition, persons with disabilities can enjoy healthy lives by identifying and realizing their aspirations, satisfying their needs and changing or coping with the environment.[5] Moreover, it is important to acknowledge that the notion of impairment varies throughout history, cultures and societies, reflecting the values and norms of a specific time and place.[6] Similarly, many persons with disabilities do not see their bodily and functional diversity as actual impairments, but as positive and normal traits of their identity or as perceived impairments.

7. Historically, persons with disabilities have been seen merely as "patients", and their views held less value than those of so-called "experts", particularly medical professionals. Under the medical model of disability, persons with disabilities were not recognized as rights-holders but "reduced" to their impairments.[7] As their disability was perceived only as a medical problem, societal responses focused on "fixing" and "curing" them, disregarding their own will and preferences. Since the 1960s, however, the disability rights movement has challenged such medical models and highlighted the negative role of barriers and oppression in the lives of persons with disabilities. Consequently, disability is nowadays understood as a social construct resulting from the interaction between persons with actual or perceived impairments and attitudinal and environmental barriers. Departing from the practice of pity and treatment, persons with disabilities should now be recognized as equal members of a diverse humanity.

8. The issue of prevention of impairments deserves clarification. States often present policy and budget commitments related to primary prevention policies as investments in the rights of persons with disabilities. While public health campaigns to prevent sickness and impairments in the general population are an important component of a State's public health policy, they should not be considered as part of the efforts to promote the rights of persons with disabilities. From a human rights perspective, States must ensure that persons with disabilities have access, on an equal basis with others, to health promotion and prevention services, including prevention of further impairments. Furthermore, States must guarantee that policies and programmes on health promotion and prevention do not stigmatize persons with disabilities, as this has a direct negative impact on their inclusion and participation in society.

[4] J. Bircher and E.G. Hahn, "Understanding the nature of health: new perspectives for medicine and public health. Improved wellbeing at lower costs", *F1000Research* 5:167 (2016). Available at https://f1000research.com/articles/5-167/v1.

[5] The Ottawa Charter for Health Promotion, adopted at the First International Conference on Health Promotion, held in Ottawa on 21 November 1986.

[6] B. Ingstad and S. R. Whyte (eds.), *Disability and Culture* (University of California Press, 1995).

[7] Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018) (CRPD/C/GC/6), para. 8.

III. The right to health of persons with disabilities

9. The right to health is recognized in various international and regional human rights instruments.[8] It encompasses both freedoms and entitlements.[9] Freedoms include the right to non-discrimination, the right to make decisions affecting one's health and bodily integrity, the right to free and informed consent, the right to be free from non-consensual medical treatment and experimentation and the right to be free from torture or cruel, inhuman or degrading treatment or punishment. Entitlements include the right to essential primary health care and the right to access essential medicines. The right to health extends to the underlying determinants of health, such as access to safe drinking water; adequate sanitation; adequate food, nutrition and housing; healthy occupational and environmental conditions; and access to health-related education and information.[10]

10. States are obliged to respect, protect and fulfil the right to health. Accordingly, States must refrain from interfering directly or indirectly with a person's health; take measures to prevent third parties from interfering with it; and take positive measures to enable and assist individuals and communities to enjoy this right. Furthermore, States must ensure that health-care goods, services and facilities are available in adequate quantity (availability); are financially, geographically and physically accessible, including accessible information and communication, without discrimination (accessibility); are respectful of medical ethics, culturally appropriate and sensitive to gender and life-cycle requirements (acceptability); and scientifically and medically appropriate and of good quality (quality). The right to health also demands the participation of the population in all health-related decision-making.[11]

11. Persons with disabilities are protected by the same general framework of the right to health as everybody else. However, the international human rights system paid little attention to their health needs until the adoption of the Convention on the Rights of Persons with Disabilities.[12] In fact, that framework allowed for restrictions on their enjoyment of different elements of the right to health in exceptional circumstances. For example, the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care established a lower standard of protection against human rights violations in health-care settings.

12. The Convention on the Rights of Persons with Disabilities[13] supersedes those previous standards. It moves away from medical and paternalistic approaches to disability towards a human rights-based approach, which considers persons with disabilities as rights-holders, rather than as mere recipients of protection, rehabilitation or welfare. Disability is no longer seen as a medical problem but as a

[8] See Universal Declaration on Human Rights (art. 25.1), International Covenant on Economic, Social and Cultural Rights (art. 12), International Convention on the Elimination of All Forms of Racial Discrimination (art. 5 (e) (iv)), Convention on the Elimination of All Forms of Discrimination against Women (arts. 11.1 (f) and 12), Convention on the Rights of the Child (art. 24), International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (arts. 28, 43.1 (e), and 45.1 (c)), Convention on the Rights of Persons with Disabilities (art. 25), European Social Charter (Revised) (art. 11), Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (art. 10) and African Charter on Human and Peoples' Rights (art. 16).

[9] Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) (E/C.12/2000/4), para. 8.

[10] Ibid., para. 11.

[11] Ibid.

[12] G. Quinn and T. Degener, "Human rights and disability: the current use and future potential of United Nations human rights instruments in the context of disability" (Geneva, OHCHR, 2002). Available at www.ohchr.org/Documents/Publications/HRDisabilityen.pdf.

[13] United Nations, *Treaty Series*, vol. 2515, No. 44910.

social construct. The Convention highlights the need to remove all societal structures, barriers and practices that limit the full and equal enjoyment of the right to the highest attainable standard of health by all persons with disabilities.

13. Many provisions of the Convention relate to the right to health, or to the underlying determinants of health. Article 25 of the Convention reaffirms the right of all persons with disabilities to the enjoyment of the highest attainable standard of health without discrimination. This includes all the elements of the right to health framework, including, inter alia, freedoms, entitlements, participation, monitoring and accountability. Article 25 also provides a non-exhaustive list of standards and obligations that States must guarantee in the implementation of the right to health, including access to sexual and reproductive health services; access to population-based public health programmes; the provision of services as close as possible to communities, including in rural areas; the provision of disability-specific health services, including prevention of further impairments; the provision to persons with disabilities of health care of the same quality as that provided to others, including on the basis of free and informed consent; the training of health professionals and the promulgation of ethical standards for public and private health care; equal access to health insurance and life insurance; and prohibition of the denial of health care or food and fluids on the basis of disability.

14. Article 25 (d) of the Convention merits particular attention. It refers to the right to free and informed consent to medical treatment and experimentation, including the right to refuse treatment, which is widely recognized in international human rights law.[14] Despite being a core element of the right to health and the right to be free from torture and ill-treatment, it is often denied to persons with disabilities. For example, articles 6 and 7 of the Convention on Human Rights and Biomedicine of the Council of Europe, adopted in 1997, allow exceptions to the right of persons with disabilities to be free from non-consensual medical hospitalization and experimentation. Similarly, certain United Nations treaty bodies and special procedures have justified the use of coercion against persons with disabilities in health care, including involuntary treatment and hospitalization, solitary confinement, the use of restraints and forced sterilization on the basis of notions of "medical necessity" and "dangerousness" (see, for example, CCPR/C/GC/35 and A/HRC/22/53). These standards and jurisprudence are contrary to the Convention on the Rights of Persons with Disabilities, which prohibits all forms of coercion on the basis of actual or perceived impairment, even if additional factors or criteria are used to justify them.

15. Furthermore, article 25 (d) of the Convention establishes the obligation to "require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent"; an obligation that is reinforced by the universal recognition of legal capacity of personal with disabilities (art. 12) and the absolute ban of deprivation of liberty on the basis of impairment, including non-consensual hospitalizations (art. 14). The Committee on the Rights of Persons with Disabilities has stressed that States parties have an obligation not to allow substitute decision-makers (e.g., guardians) to provide consent on behalf of persons with disabilities.[15] Instead, supported decision-making regimes should be made available and health and medical personnel should take measures to ensure that supporters are respectful of the individual's will and preferences and do

[14] International Covenant on Civil and Political Rights (art. 7), Universal Declaration on Bioethics and Human Rights (arts. 5 and 6) and Convention on Human Rights and Biomedicine (art. 5). The right to free and informed consent has also been interpreted to be part of the right to security of the person, the right to freedom from torture and cruel, inhuman, and degrading treatment or punishment, the right to privacy and the right to the highest attainable standard of health.

[15] Committee on the Rights of Persons with Disabilities, general comment No. 1 (2014) (CRPD/C/GC/1), para. 41.

not substitute or have undue influence over the decisions of persons with disabilities.[16] In cases where significant efforts have been made and it is not possible to obtain an individual's free and informed consent or to ascertain their will and preferences, including through the provision of support and accommodations, the standard of "best interpretation of the will and preference" should be applied as a last resort.[17]

16. Other provisions of the Convention complement article 25. For example, article 5 prohibits all forms of discrimination, including in health care; article 9 requires the accessibility of all medical facilities, transportation, information, communications and services; article 10 reaffirms the right to life of persons with disabilities; articles 15 and 17 recognize the right to be free from torture or cruel, inhuman or degrading treatment or punishment and the right to personal integrity, including freedom from non-consensual medical treatment; article 19 provides for the right to live independently and be included in the community, which precludes segregation and institutionalization in health-care settings; article 22 recognizes the right to privacy, including privacy of health-related information; article 23 provides for the right of persons with disabilities to access reproductive and family planning education and to retain their fertility and decide on the number and spacing of their children, which precludes forced sterilization; article 21 addresses access to information, which combats health illiteracy; and article 28 addresses the rights to adequate standard of living and social protection, which cover social determinants of health.

17. Article 26 of the Convention complements the obligation to guarantee health services needed by persons with disabilities specifically because of their impairment. It requires States to implement comprehensive habilitation and rehabilitation services and programmes,[18] including in the area of health, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. These services and programmes should begin at the earliest possible stage; be based on a multidisciplinary assessment; support participation and inclusion; be voluntary; and be available as close as possible to people's communities. Furthermore, article 26 requires States to train professionals and staff working in habilitation and rehabilitation and to promote the availability, knowledge and use of assistive devices and technologies.

18. The right to health contains both obligations of immediate effect and an obligation of progressive realization. The former include core obligations such as non-discrimination; freedom from non-consensual medical treatment and experimentation; access to food, basic shelter, housing and sanitation and safe and potable water; and access to essential primary health care and medicines.[19] The latter imposes an obligation on States to move as expeditiously and effectively as possible, making full use of their available resources, including those made available through international cooperation, towards the full realization of the right to health.[20] Such steps must be deliberate, concrete and targeted,[21] and include the adoption of

[16] Ibid.

[17] Ibid., para. 21.

[18] Habilitation and rehabilitation describe a broad range of responses to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life. Habilitation refers to services targeting those who acquire impairments congenitally or early in life, whereas rehabilitation refers to services for those who acquire an impairment later in life.

[19] Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) (E/C.12/2000/4), para. 43.

[20] Ibid., paras. 31 and 32.

[21] Ibid., para. 30.

indicators and benchmarks to properly monitor progress over time. In the view of the Special Rapporteur, access to essential habilitation and rehabilitation, to essential assistive devices and to essential health services needed by persons with disabilities owing to their impairment should be considered as core obligations that are not subject to progressive realization.

19. States have an obligation to protect persons with disabilities against violations of their right to health within their territory and/or jurisdiction by third parties. The Convention specifically requests States parties to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise (art. 4.1 (e)); and to ensure that private entities offering facilities and services open or provided to the public take into account all aspects of accessibility (art. 9.2 (b)). States should prevent, address and redress human rights abuses committed by non-State actors in the private sector as outlined in the Guiding Principles on Business and Human Rights (A/HRC/17/31, annex).

20. The commitment to leave no one behind demands that all persons with disabilities can enjoy the full range of opportunities created by the 2030 Agenda for Sustainable Development (General Assembly resolution 70/1), including the various health-related goals, which represent an opportunity to advance the right to health of persons with disabilities. The Convention on the Rights of Persons with Disabilities offers normative guidance for the implementation of the Sustainable Development Goals from a human rights-based perspective. Disaggregated data, as called for in Goal 17, are needed to measure whether persons with disabilities are being left behind in access to health care.

IV. Challenges and concerns

21. The Special Rapporteur has identified three main challenges associated with the enjoyment of the right to health by persons with disabilities: (a) health and health-care inequalities; (b) barriers to accessing health-care services; and (c) specific human rights violations in health-care settings.

A. Health and health-care inequalities

22. Persons with disabilities experience significant health and health-care inequalities. Secondary and co-morbid conditions are common among persons with disabilities and include chronic health conditions such as high blood pressure, cardiovascular diseases and diabetes. Although some of these outcomes are impairment-related, inequities in access to health care, health literacy and economic resources are at the root of the vulnerability to many of these conditions and/or contribute to aggravating them. For example, studies show that on average persons with intellectual disabilities die 15 to 20 years earlier than the general population owing, to a significant extent, to neglect, poor treatment and failure to undertake routine screening, health promotion and prevention activities.[22] Similarly, the life expectancy of adults with psychosocial disabilities is about 20 to 25 years shorter owing to multiple factors, including somatic disease associated with antipsychotic medication.[23]

[22] Health Quality Improvement Partnership, *The Learning Disabilities Mortality Review*, annual report 2017.

[23] S. Saha, D. Chant and J. McGrath, "A systematic review of mortality in schizophrenia: is the differential mortality gap worsening over time?", *Archives of General Psychiatry*, vol. 64, No. 10 (2007), pp. 1123–1131.

23. Furthermore, persons with disabilities are significantly more likely to need health-care services than persons without disabilities, while also being more likely to report not receiving them.[24] For example, a study found that persons with disabilities had thrice the level of unmet health-care needs than those without disabilities.[25] Evidence also suggests that persons with disabilities are disadvantaged in accessing primary care, which perpetuates a cycle of poorer health outcomes for them. Children with disabilities often do not receive basic treatment for common childhood illnesses, which may become life threatening if left untreated.[26] There is a false assumption that persons with disabilities always require specialized services, when the majority of their health needs can be met by primary care.

24. Access to health-related habilitation and rehabilitation services is limited among persons with disabilities. While different categories of people require rehabilitation services, coverage is generally low across the diversity of persons with disabilities.[27] This includes access to physical therapy, speech and language therapy and psychosocial rehabilitation. Coverage is particularly limited in low- and middle-income countries, where in some settings only 3 to 5 per cent of persons with disabilities benefit from those services.[28] Moreover, evidence indicates that in many low- and middle-income countries only 5 to 15 per cent of persons with disabilities requiring assistive devices and technologies have access to them.[29]

25. Persons with disabilities face significant challenges to accessing specialist health-care services, which are essential for many groups. For instance, a significant number of newborns with congenital impairments such as spina bifida and hydrocephalus die before one month of age owing to the absence of specialized treatment.[30] Likewise, the lack of accurate diagnosis and effective treatments for the majority of rare diseases represents a challenge worldwide.[31]

26. Generally, persons with disabilities are not targeted by strategies for health promotion and disease prevention. Children with disabilities are often excluded from immunization programmes, even in countries where overall immunization rates have increased dramatically.[32] Several studies have shown that women with disabilities have limited access to cancer screening services.[33] Persons with albinism lack access to adequate sun protection. Deaf persons experience significant knowledge gaps in preventive health. Similarly, efforts to promote healthy behaviours, such as regular

[24] WHO and World Bank, *World Report on Disability* (2011), pp. 60–62.

[25] M. A. McColl, A. Jarzynowska and S. E. D. Shortt, "Unmet health care needs of people with disabilities: population level evidence", *Disability and Society*, vol. 25, No. 2 (2010), pp. 205–218.

[26] WHO and United Nations Children's Fund (UNICEF), "Early childhood development and disability: a discussion paper" (2012), p. 17.

[27] T. Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities", discussion paper commissioned by the Special rapporteur on the rights of persons with disabilities (2018), pp. 21–26. Available at http://disabilitycentre.lshtm.ac.uk/resources/.

[28] Ibid, p. 24.

[29] WHO, Assistive technology fact sheet (18 May 2018), www.who.int/en/news-room/fact-sheets/detail/assistive-technology.

[30] WHO, Congenital anomalies fact sheet (7 September 2016), www.who.int/news-room/fact-sheets/detail/congenital-anomalies.

[31] European Commission, *Rare diseases — a major unmet medical need* (2017), p. 9.

[32] UNICEF, "Disability prevention efforts and disability rights: finding common ground on immunization efforts", working paper, available at www.unicef.org/disabilities/files/UNICEF_Immunization_and_Disability_Paper_FINAL.pdf.

[33] J. Angus, L. Seto, N. Barry et al., "Access to cancer screening for women with mobility disabilities", *Journal of Cancer Education*, vol. 27, No. 1 (March 2012), pp. 75–82; K. Eaters and A. Cotton, "Barriers to breast cancer screening in Australia: experiences of women with physical disabilities", *Journal of Clinical Nursing*, vol. 24, Nos. 3 and 4 (March 2012), pp. 563–72.

exercise and good diet, generally are not accessible and place little emphasis on addressing the needs of persons with disabilities.[34]

27. While persons with disabilities are as sexually active as everyone else, they have limited access to sexual and reproductive health-care services. Several studies have found that they have lower levels of access to quality services than persons without disabilities, including lower access to sexuality education and knowledge on sexual and reproductive health and rights.[35] Young people with disabilities, for example, generally show lower levels of knowledge concerning HIV transmission and prevention.[36] Women and girls with disabilities also report that their needs and expectations are not met by antenatal and gynaecological services.[37]

28. Persons with disabilities experience great inequalities in oral health and access to dental health care. Most dental care needs of persons with disabilities, as those of the general population, are not complex and can be dealt with in primary care and community settings.[38] However, they experience greater levels of oral disease than the rest of the population, as well as higher levels of unmet needs for dental care.[39] Particularly high levels of untreated dental disease have been found in persons with disabilities with high support needs and those in institutional settings.[40]

29. Often persons with disabilities do not receive the mental health care they may need and seek. As raised by the Special Rapporteur on the right to health, there is an alarming "global burden of obstacles" that hinders the implementation of the right to mental health, including the dominance of a "biomedical model", power asymmetries and the biased use of evidence in mental health (see A/HRC/35/21). This approach to mental health has contributed to the stigma, exclusion, neglect, coercion and abuse of persons with disabilities, particularly those with psychosocial and intellectual disabilities, dementia and autism, and has further limited the policy responses to provide mental health care and psychosocial support to those who seek it. For example, public expenditures on mental health services are mostly directed to in-patient care, especially psychiatric hospitals and residential institutions, while community-based and non-coercive psychosocial services are barely funded.[41]

30. The underlying determinants of health are also of concern. Persons with disabilities are more likely to experience poverty and social exclusion, which increases both the likelihood of ill-health and of facing barriers to accessing health care. Persons with disabilities are also at higher risk of experiencing violence (see A/70/297). Adults with disabilities run twice the risk of violence as persons without disabilities, rising to six times the risk in the case of adults with psychosocial disabilities.[42] Children with disabilities are six times as likely as other children to experience violence and abuse.[43] Children with psychosocial or intellectual disabilities have a higher prevalence and risk of violence than children with other

[34] J. H. Rimmer, "Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions", *Physical Therapy*, vol. 79, No. 5 (1 May 1999), pp. 495–502.

[35] S. H. Braathen, P. Rohleder and G. Azalde, *Sexual and reproductive health and rights of girls with disabilities: a review of the literature* (SINTEF, 2017), pp. 13–15. Available from www.sintef.no.

[36] Ibid., pp. 13–14.

[37] Ibid., p. 16.

[38] World Dental Federation, "Oral health and dental care of people with disabilities", policy statement adopted by the FDI General Assembly, Poznań, Poland, September 2016.

[39] D. Faulks and others, "The value of education in special care dentistry as a means of reducing inequalities in oral health", *European Journal of Dental Education*, vol. 16 (2012), pp. 195–201.

[40] Ibid.

[41] WHO, *Mental Health Atlas 2014* (Geneva, 2015), p. 31.

[42] T. Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities" (note 27 above), p. 8.

[43] Ibid.

disabilities. Furthermore, many health-related problems common among children with disabilities can be attributable to restricted access to basic underlying determinants of health, like safe drinking water, bed nets and nutrient-rich foods.[44]

B. Barriers to accessing health-care services

31. Stigma and stereotypes are major barriers to accessing health care. Although evidence proves otherwise, misconceptions about the health of persons with disabilities have led to the assumption that their needs cannot be addressed by primary health services, or that they are not good candidates for health promotion and disease prevention. Stigma and stereotypes also lead to negative and hostile attitudes among service providers. For example, they play a significant role in limiting the sexual and reproductive health and rights of girls and young women with disabilities (see A/72/133). Furthermore, shame and stigma associated with disability prevent persons with disabilities and their families from seeking medical attention or rehabilitation.

32. There is a need to rethink and review international health-related tools and standards that can contribute to further stigma and pathologization of disability. Diagnostic tools and classification instruments such as the International Classification of Diseases and the Diagnostic and Statistical Manual of Mental Disorders can reinforce public stigma and cause people to avoid seeking health care for fear of being labelled.[45] Similarly, health metrics such as the quality-adjusted life year and the disability-adjusted life year, which are widely used to estimate longevity and health-related well-being and to guide the allocation of resources, are controversial for the ethical implications of the disability weights and their impact on policymaking.[46]

33. Health-related habilitation and rehabilitation services are scarce for persons with disabilities. Evidence suggests that the demand for rehabilitation is much higher than what these services can provide.[47] Where rehabilitation is available, efforts have been concentrated disproportionately in hospital-centred rather than locally available services. Physical therapies are also more commonly available than other interventions, such as speech and language therapy. The shortage of professionals who deliver rehabilitation services (e.g., physiotherapists, occupational therapists, speech and language therapists, optometrists, audiologists or general practitioners working on rehabilitation), and their concentration in urban areas, also represent significant barriers for those seeking rehabilitation, particularly in low- and middle-income countries.[48] Specialist health services and professionals are usually scarce in low- and middle-income countries.

34. Persons with disabilities also face restrictions in accessing health care owing to the lack of physical accessibility of buildings, equipment and services. Furthermore, the distance to and from health-care facilities in rural and remote areas constitutes a significant barrier to persons with disabilities owing to poverty, the absence of accessible and affordable transport and the lack of family and community support. Other common accessibility barriers include the lack of information in accessible

[44] UNICEF, "Disability prevention efforts and disability rights" (note 32 above), p. 3.

[45] D. Ben-Zeev, M. A. Young and P. W. Corrigan, "DSM-V and the stigma of mental illness", Journal of Mental Health, vol. 19, No. 4 (2010), pp. 318–27.

[46] D. A. Pettitt and others, "The limitations of QALY: a literature review", *Journal of Stem Cell Research and Therapy*, vol. 6, No. 4 (2016), p. 4; R. Parks, "The rise, critique and persistence of the DALY in global health", *The Journal of Global Health* (1 April 2014), available at www.ghjournal.org/the-rise-critique-and-persistence-of-the-daly-in-global-health/.

[47] WHO, "The need to scale up rehabilitation", available at www.who.int/disabilities/care/NeedToScaleUpRehab.pdf?ua=1.

[48] WHO and World Bank, *World Report on Disability* (2011), p. 66.

formats (e.g., in Braille or plain language); communication barriers (e.g., the lack of sign language interpretation or the absence of training for service providers in communicating with children and adults with intellectual disabilities); relatives and caregivers acting as gatekeepers to information and services; and the isolation of persons with disabilities in institutions, camps, family homes or group homes (see A/72/133).

35. Financial barriers to accessing health care are significant among persons with disabilities. While their health-care costs are often higher, they are less likely to be employed and on average are poorer than those without disabilities. Evidence shows that 51 to 53 per cent of persons with disabilities cannot afford health care, compared with 32 to 33 per cent of persons without disabilities.[49] Persons with disabilities are also 50 per cent more likely to experience catastrophic health expenditure (out-of-pocket spending exceeding a household's ability to pay), which pushes them into poverty.[50] The high pricing of medicines and the lack of or limited access to generic medicines is also a significant barrier for those who need to take medication for prolonged time periods.

36. Discrimination in health insurance is another major barrier to accessing health care. Coverage rates are frequently low because insurance companies often refuse to offer health-care insurance to persons with disabilities due to pre-existing conditions. Discrimination may also occur in the way that insurance plans are designed, limiting the benefits or coverage that a person with disabilities can receive or increasing disproportionally the cost of the insurance premium. Such practices violate the Convention on the Rights of Persons with Disabilities.

37. Acceptability and quality of health-care services are also a challenge. Health services and programmes are not generally adapted to the diversity of persons with disabilities, including gender, life-cycle and intercultural requirements. Indeed, many children with disabilities do not transition from paediatric to adult health care owing to the unavailability of specialists or the reluctance of general practitioners to treat persons with disabilities. Additionally, services do not always respect confidentiality and the privacy of persons with disabilities. For example, deaf people often face breaches of their privacy because family members may be needed to act as their interpreters.[51] Furthermore, in many countries, access to health care and rehabilitation services is conditioned upon obtaining a disability certificate, which constitutes an arbitrary requirement.

C. Specific human rights violations in health-care settings

38. In many countries, persons with disabilities are denied treatment on the basis of their disability. While justifications range from lack of accessibility to insufficient health insurance coverage, the assumption that persons with disabilities have less value or enjoy less quality of life lies at the root of many practices. Afflictions and medical symptoms of persons with disabilities are often seen as part of their impairment, resulting in lack of treatment. Even more troublesome, persons with disabilities are often deemed as unworthy of treatment; many children and adults with disabilities are not offered or are denied treatment, including life-saving and life-extending treatments, as such interventions are considered pointless and inefficient. For example, a study found that many health-care providers do not support standard emergency interventions, such as a thoracotomy, for patients with fresh spinal cord

[49] Ibid.

[50] Ibid., p. 67.

[51] Y. Bat-Chava, D. Martin, and J. G. Kosciw, "Barriers to HIV/AIDS knowledge and prevention among deaf and hard of hearing people", *AIDS Care*, vol. 17, No. 5 (2005), pp. 623–634.

injury.[52] Failure to ensure access to life-saving treatment and medication for the relief of pain and suffering threatens the rights to life, health and freedom against cruel, inhuman and degrading treatment.

39. Denial of free and informed consent is a widespread violation of the right to health of persons with disabilities. Standard informed consent processes generally rely on written forms, which are inaccessible to blind persons and those who need interpretation or communication support. Most national legislations, particularly mental health laws, provide for the involuntary hospitalization and treatment of persons with disabilities on the grounds of their actual or perceived impairment, by itself or in conjunction with other factors like "medical necessity" and "dangerousness". In many countries, guardians and caregivers are allowed to provide consent to treatment on behalf of a person with disabilities, including experimental procedures. There is also an increase of mandatory outpatient treatment, which not only increases involuntary interventions but also allows for other forms of abuse such as illegal curfews and prohibitions.[53] Rates of involuntary hospitalization and treatment are exceptionally elevated in high-income countries, with numbers rapidly increasing in several European countries.[54] In this context, the introduction of new psychotropic drugs with a digital ingestion tracking system ("digital pills") is of great concern owing to their potential use for coercive treatment. It must be stressed that coercive practices have not only social and psychological effects but also a negative impact on physical health.

40. Persons with disabilities, especially girls and women, face serious human rights violations in the exercise of their sexual and reproductive health and rights. They are generally prevented from taking autonomous decisions with regard to their reproductive and sexual health and are regularly exposed to violence, abuse and harmful practices, including forced contraception, forced abortion and forced sterilization (see A/72/133). Evidence indicates that the sterilization of women and girls with intellectual and psychosocial disabilities continues to be prevalent.[55] Those who conceive run the risk of having their children taken away by the State or by their families.[56] Having a guardian or being placed in an institution increases the risk of being subjected to any of these practices.

41. There are a growing number of treatments and interventions whose effectiveness is uncertain or deemed controversial. These include, for example, electroconvulsive therapy; psychosurgery; experimental mercury detoxification treatments, harsh behavioural modification regimes and packing for autistic children; conductive education for children with cerebral palsy; and limb-lengthening for children with restricted growth.[57] Many of these interventions are invasive, painful and irreversible, and therefore may amount to torture or ill-treatment if applied involuntarily. In the case of children, these practices also contradict the principle of respect for the

[52] K. A. Gerhart and others, "Quality of life following spinal cord injury: knowledge and attitudes of emergency care providers", *Annals of Emergency Medicine*, vol. 23, No. 4 (1994), pp. 807–812.

[53] A. Molodynsky, J. Rugkåsa, and T. Burns, *Coercion in Community Mental Health Care International Perspectives* (Oxford University Press, 2016).

[54] H. J. Salize and H. Dressing, "Epidemiology of involuntary placement of mentally ill people across the European Union", *British Journal of Psychiatry*, vol. 184, No. 2 (February 2004), pp. 163–168; United Kingdom Department of Health and Social Care, "The independent review of the Mental Health Act", interim report, May 2018.

[55] L. Servais, R. Leach, D. Jacques and J. P. Roussaux, "Sterilisation of intellectually disabled women", *European Psychiatry*, vol. 19, No. 7 (2004), pp. 428–432; L. Lennerhed, "Sterilisation on eugenic grounds in Europe in the 1930s: news in 1997 but why?", *Reproductive Health Matters*, vol. 5, No. 10 (1997), pp. 156–161.

[56] T. Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities" (note 27 above), p. 31.

[57] Ibid, p. 10.

evolving capacities of children with disabilities and their right to preserve their identities.

42. Exploitation, violence and abuse against persons with disabilities within health-care settings are also frequent. Seclusion and restraints, including chemical restraints, are regularly used in many mental health services. These practices have no therapeutic objective and are frequently a consequence of the lack of support for people experiencing an emotional crisis and severe distress (see A/HRC/37/56). They are also used as a punishment to enforce compliance to treatment and medication. Likewise, overmedication of autistic persons, persons with psychosocial disabilities and older persons with disabilities is a widespread practice that can cause sedation, injury, cognitive or behavioural changes and death. Like all those placed in segregated settings, persons with disabilities are also at high risk of physical and sexual abuse and exploitation in places such as psychiatric institutions, nursing homes and residential treatment facilities for children.

D. Multiple and intersectional forms of discrimination

43. Persons with disabilities are a heterogeneous group with a wide range of impairments and identity traits such as race, colour, sex, sexual orientation, gender identity, language, religion, national, ethnic, indigenous or social origin and age. The interplay of these traits produces further health and health-care inequalities and barriers. For example, communication barriers are particularly high for migrants, refugees and asylum seekers with disabilities, and financial barriers are especially problematic for certain groups, such as Roma and indigenous persons with disabilities.[58]

44. Women with disabilities have consistently less access to health-care services and programmes than women without disabilities and men with disabilities.[59] They also experience worse health care and preventive care. Likewise, they are more likely to be subjected to violence, abuse and neglect and to experience human rights violations in the exercise of their sexual and reproductive health and rights. Women with severe impairments have higher chances of facing unmet needs and human rights violations in health-care settings.

45. Children and older persons with disabilities also report high levels of unmet health needs. A significant number of them are placed in institutions, considerably reducing their chances to receive proper nutrition and medical attention and increasing their risk of developing secondary conditions.[60] They are also at a particularly high risk of receiving treatment without their informed consent. In no case can the access to health-care of persons with disabilities be conditioned on their placement in residential institutions.

46. Furthermore, in recent years the number of children diagnosed with autism, attention deficit hyperactivity disorder and other conditions has grown exponentially, prompting a rapid increase of the prescription of stimulants and other psychotropic

[58] European Union Agency for Fundamental Rights (FRA), *Inequalities and multiple discrimination in access to and quality of healthcare* (2013), pp. 47–51.

[59] D. L. Smith, "Disparities in health care access for women with disabilities in the United States from the 2006 National Health Interview Survey", *Disability and Health Journal*, vol. 1, No. 2 (2008), pp. 79–88; D. Sakellariou and E. S. Rotarou, "Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data", *BMJ Open*, vol. 7, No. 8 (2017).

[60] K. Maclean, "The impact of institutionalization on child development", *Development and Psychopathology*, vol. 15, No. 4 (2003), pp. 853–884; F. D. Wolinsky and others, "The risk of nursing home placement and subsequent death among older adults", *Journal of Gerontology*, vol. 47, No. 4 (1992), pp. 173–182.

medications. These practices are generally the result of outdated understandings of disability and the lack of appropriate support. The Special Rapporteur stresses that pathologization and medicalization of the behaviour of children with disabilities represent an unacceptable practice that contradicts the principle of respect for the difference and acceptance of persons with disabilities as part of human diversity.

47. Persons with disabilities deprived of their liberty or in refugee camps face significant challenges in accessing health care owing to the lack of accessible facilities and communication support. The lack of access to medical attention in urgent cases and for those who require specialized treatment or surgery is particularly problematic.

V. Implementing the right to health of persons with disabilities

48. States can take a number of steps to improve the realization of the right to health of persons with disabilities, including reviewing their legal and policy frameworks; taking concrete measures in the areas of universal health coverage, accessibility, non-discrimination and participation; and mobilizing resources for the implementation of the relevant measures.

A. Legal framework

49. States must establish an enabling legislative and regulatory framework for the right to health of persons with disabilities. Laws that protect the health of the population should be reviewed in the light of the international framework for the right to health and the rights-based approach to disability. These provide that health-care goods, services and facilities should be made available, accessible, affordable, acceptable and be of good quality for persons with disabilities. Provisions that exclude or restrict access of persons with disabilities to health-care services, including sexual and reproductive health services, should be amended to facilitate universal and equitable access.

50. States must immediately repeal all discriminatory legislation that allows the hospitalization and treatment of persons with disabilities without their free and informed consent, and/or when decided by a third party, including guardians, family members and health professionals. States should instead ensure that advance planning and other forms of supported decision-making are available to those who may need them. Furthermore, States should consider allowing children to consent to certain medical treatments and interventions without the permission of a parent, caregiver or guardian, such as HIV testing and sexual and reproductive health services,[61] and consider adopting protocols to regulate the informed consent of children with disabilities to all surgical and other invasive procedures. Legislation must provide for effective remedies for persons with disabilities whose right to health has been violated, including adequate, effective and prompt redress and reparation for harm suffered, as well as judicial and administrative sanctions on perpetrators.

B. Policy framework

51. States must mainstream the rights and needs of persons with disabilities in both primary and specialist health-care policies and programmes. Access to primary care is essential to identify and address the general health requirements of persons with disabilities, but also to respond to their additional specific health needs, either directly

[61] Committee on the Rights of the Child, general comment No. 15 (2013) (CRC/C/GC/15), para. 31.

or through referral to specialist services. Excessive reliance on specialist care can prevent primary care involvement, lead to unnecessary diagnosis and treatment and make the health services more expensive. Therefore, secondary and tertiary health-care services should support and work in close partnership with primary care providers to respond to the health needs of persons with disabilities within their communities. Health promotion activities must be inclusive of persons with disabilities and address the particular health conditions they face, including their underlying determinants of health. Early identification and intervention strategies are also required to facilitate timely access to health-care services and to minimize and prevent further impairments. It is important to ensure these do not contribute to further discrimination and exclusion from mainstream services, such as education.[62]

52. States should establish a policy framework to organize, strengthen and extend comprehensive health-related habilitation and rehabilitation services and programmes for persons with disabilities. Efforts should include improving integration of health-related habilitation and rehabilitation in primary health care; building comprehensive service delivery models; developing a multidisciplinary rehabilitation workforce; and ensuring that rehabilitation is included within health-care budgets.[63] The policy framework should also ensure that persons with disabilities have access to accessible, adequate and affordable assistive devices and technologies.[64] While community-based rehabilitation can be effective in improving the health and quality of life of persons with disabilities, these interventions are usually restricted in their geographical coverage, limited in scope and unsustainable.[65] Ensuring access to health-related habilitation and rehabilitation services, as well as assistive devices and technologies, is a State obligation and responsibility that cannot be handed over to non-profit organizations and charities.

53. States must ensure that health care is provided as close as possible to the communities where persons with disabilities live, including rural and remote areas. Delivery of services at or close to home can improve access to health care. States need to ensure that their rural development strategies include measures to promote access to quality health care for persons with disabilities, including community-based strategies and outreach services (e.g. mobile clinics, health caravans, telemedicine and phone-based strategies). States should also consider adopting interventions aimed at improving the demand for health-care services among persons with disabilities themselves (e.g., text message reminders, peer health promoters and home visits).

C. Universal health coverage

54. Achieving universal health coverage is central to the Sustainable Development Goals. The goal of universal health coverage requires that all people and communities receive the essential health services they need, without being exposed to financial hardship. Goal 3 includes an explicit commitment to "achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all " (target 3.8) and to "ensure universal access to sexual and

[62] WHO and UNICEF, "Early childhood development and disability: a discussion paper", (2012) p. 22.

[63] WHO, "Rehabilitation 2030: a call for action", meeting report, 2017, available at www.who.int/disabilities/care/Rehab2030MeetingReport2.pdf?ua=1.

[64] For further guidance on how to ensure access to assistive devices and technologies, see A/71/314.

[65] V. Iemmi and others, "Community-based rehabilitation for people with disabilities in low- and middle-income countries: a systematic review", Campbell Systematic Reviews, 2015. Available from https://campbellcollaboration.org/.

reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes" (target 3.7). Health-related indicators of Goal 3 also acknowledge a wide range of services, including health promotion, prevention, treatment, rehabilitation and palliation, and the need to measure the coverage of essential health services among the general and the most disadvantaged populations, such as persons with disabilities.

55. Against this background, universal health coverage can be an important instrument to increase the access of persons with disabilities to health care. However, to make it happen, States need to take into account persons with disabilities when considering expanding the population covered by health-care services; the services included in the benefits package; and the proportion of cost covered. In particular, States need to ensure that the implementation of universal health coverage — from packages of essential health services to health financing reforms — includes the full range of health-care services that persons with disabilities may need, including health-related habilitation and rehabilitation, assistive devices and technologies[66] and essential medicines. For example, in Sierra Leone, the Disability Act of 2011 allows for persons with disabilities to access free medical services in all public health institutions. Discussions on universal health coverage should take into account increasingly available health-care technology and treatments that have the potential to increase life expectancy and the quality of life of persons with disabilities (e.g., surgeries for children with spina bifida or cardiac surgeries for children with Down syndrome).

D. Accessibility

56. States must ensure the full accessibility of health-care services and programmes. All public and private health-care facilities and services must take into account all aspects of accessibility for persons with disabilities, including the accessibility of infrastructure, equipment and information and communications. Accessible transport must be also guaranteed, as otherwise persons with disabilities cannot reach health-care services or facilities.

57. All information and communications pertaining to the provision of health care, including electronic services and emergency services, should be accessible to persons with disabilities, including through sign language, Braille, accessible electronic formats, alternative script, easy-to-read formats and augmentative and alternative modes, means and formats of communication.[67] All public health campaigns must be also accessible and inclusive of persons with disabilities. For instance, in Nigeria, in order to address accessibility concerns, sign language interpreters have been posted in hospitals to focus on the sexual and reproductive health-care needs of women with disabilities within the Federal Capital Territory.

E. Non-discrimination

58. States have an obligation to provide health-care to persons with disabilities without discrimination. States must therefore eliminate discrimination against persons with disabilities in law, policy and practice, and prohibit all forms of discrimination in the provision of health care. For instance, States should refrain from

[66] States should develop a list of essential assistive products according to their national needs and available resources on the basis of the WHO priority assistive products list (see A/71/314).

[67] Committee on the Rights of Persons with Disabilities, general comment No. 2 (2014) (CRPD/C/GC/2), para. 40.

providing health-care services predominantly in institutional and residential settings. In addition, States need to take measures to provide reasonable accommodation to persons with disabilities so that they can access and enjoy these services and facilities on an equal basis with others. While accessibility is subject to progressive realization, States have an immediate obligation to provide reasonable accommodation so that persons with disabilities can access health-care right away.

59. States must prohibit and combat discrimination against persons with disabilities in the provision of health insurance. Denial of health insurance to persons on the basis of their disability must be legally banned. States should also consider adopting regulations to ensure that insurance plans and premiums are fixed in a fair and reasonable manner. In Mexico, for example, the Supreme Court of Justice has ruled that insurance companies cannot discriminate against persons with disabilities in the provision of health insurance, and should adopt policies and plans for their inclusion.

60. Health systems must respond to the needs of the diversity of persons with disabilities. States need to pay attention to the existing layers of identities within the disability community in order to adequately address the inequalities and intersectional discrimination experienced by persons with disabilities. States should consider developing and implementing policies and practices targeting the most marginalized groups of persons with disabilities (e.g., persons with multiple or severe impairments, rare diseases or deaf-blindness) in order to accelerate or achieve de facto equality in access to health care.

F. Participation

61. States must consult and actively involve persons with disabilities, including children with disabilities, in the implementation of health-care services. Persons with disabilities know best which barriers they face in their own contexts and how they affect their lives. Their participation ensures that States' health policies and programmes are devised on the basis of their needs and preferences, which can result in greater efficiency and a more equitable use of resources. For example, in Bosnia and Herzegovina, cooperation between the government and organizations of persons with disabilities led to the creation of accessibility standards for health-care institutions. The Special Rapporteur has developed a thematic study on the right of persons with disabilities to participate in decision-making that provides specific guidance on how to meet this obligation (see A/HRC/31/62).

62. States should be aware that the views of persons with disabilities may conflict with those of health professionals, as the latter are usually trained to act in the best interest of the patient, and many hold paternalistic and medicalized views of disability. Persons with disabilities should be recognized as the main interlocutors when it comes to their own rights and States should always give priority to their opinions in matters affecting them. Similarly, umbrella organizations of persons with disabilities might have different views from specific groups, thus the importance of consulting and engaging directly with all stakeholders. States should also ensure that the diversity of persons with disabilities is represented and consulted in decision-making processes related to the right to health.

G. Accountability

63. Accountability is crucial for ensuring that health-care services are inclusive and respectful of the rights of persons with disabilities. National health strategies and plans should have clear lines of accountability, with indicators and benchmarks that facilitate the monitoring of the implementation of the right to health of persons with

disabilities. Quality disaggregated data are also needed to identify gaps and outcomes in health care. The governmental focal points and coordination mechanisms for the implementation of the Convention on the Rights of Persons with Disabilities, as required by its article 33 (1), should facilitate and support the implementation of health strategies and plans from the perspective of a rights-based approach. To prevent the occurrence of all forms of exploitation, violence and abuse in the provision of health care, States must ensure the independent monitoring of all health facilities and programmes, as well as the establishment of appropriate and effective safeguards.

64. States must provide for enforcement mechanisms to guarantee the effective implementation of the right to health of persons with disabilities. Any person or group of persons with disabilities that has been the victim of a violation of the right to health should have access to effective judicial or other appropriate remedies.[68] These remedies should include adequate reparations, including restitution, compensation, satisfaction and guarantees of non-repetition, as appropriate. National human rights institutions and independent mechanisms to promote, protect and monitor the implementation of the Convention should be mandated to carry out inquiries and investigations (art. 33 (2)), as well as provide assistance to persons with disabilities in accessing legal remedies. Consumer protection agencies should conduct inquiries and investigations on discrimination against persons with disabilities in the provision of health insurance and life insurance.

H. Resource mobilization

65. States have an obligation to take immediate steps, making full use of their available resources, including those made available through international cooperation, to ensure that persons with disabilities have access to health care. In many countries, health-related habilitation and rehabilitation services and programmes, including the provision of assistive devices and technologies, are underfunded. Consequently, many persons with disabilities do not have access at all to those services or, at most, depend on non-profit organizations or private charities to access them. Government health planning and budgeting need to incorporate the specific health services needed by persons with disabilities, as well as the particular needs of persons with disabilities across all budget lines. Social protection systems can also help to address the additional costs that persons with disabilities face in accessing health care, and to facilitate support services for those who may need it (see A/70/297).

66. In considering the allocation of resources, States should pay attention to their core obligations in relation to the right to health, particularly ensuring essential primary health care for all persons with disabilities. Ensuring financial protection for persons with disabilities should be a key consideration in decision-making for universal health coverage. States should not adopt retrogressive measures that affect the right to health of persons with disabilities, as well as refrain from funding practices contrary to the human rights-based approach to disability (e.g., institutionalization or coercive health interventions).

I. Awareness-raising

67. States Parties must adopt immediate, effective and appropriate measures to raise awareness throughout society regarding persons with disabilities and their health needs from a rights-based approach. Persons with disabilities should not be seen as

[68] Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) (E/C.12/2000/4), para. 59.

ill or as patients, but rather as rights-holders in the same way as every member of society. States must also foster respect for the right to health of persons with disabilities through the sensitization and training of health-care professionals and staff. Training should also address the intersecting forms of discrimination that affect persons with disabilities in the enjoyment of the right to health. Medical and health professional schools should review their curricula to ensure that the education they offer adequately reflects the health-care needs and rights of persons with disabilities. Furthermore, suitable qualified persons with disabilities should be supported in their efforts to be trained as health professionals themselves.

68. Health literacy strategies targeting persons with disabilities should be implemented, including through the provision of health-related information in a variety of formats, so that persons with disabilities can be in a position to obtain, process and understand basic health information and services needed to make appropriate health decisions. In Ecuador, for example, the Ministry of Public Health has developed a manual on sexual and reproductive health for persons with disabilities, which establishes guidelines for service providers on how to ensure the access of persons with disabilities to information and services.

69. Awareness-raising campaigns and training programmes to promote the right to health of persons with disabilities must adopt a human rights-based approach to disability. Public fundraising campaigns in support of habilitation and rehabilitation services, such as telethons, reinforce a charity approach and a pervasive pathologizing view of disability. Similarly, public delivery events of assistive devices and technologies, such as wheelchairs and other mobility devices, are contrary to respect for the inherent dignity of persons with disabilities and reinforce a charity approach to disability.

J. International cooperation

70. International, South-South and triangular cooperation play a crucial role in supporting national efforts to implement the Sustainable Development Goals. States and international donors need to ensure that all international cooperation in the area of health, including international development programmes, is inclusive of, and accessible by, persons with disabilities. International cooperation in the area of health must also be consistent with the human rights of persons with disabilities and provided in a sustainable and culturally appropriate manner. International organizations, non-profit organizations, charities and other organizations operating in national contexts should refrain from implementing projects contrary to the human rights-based approach to disability (see A/HRC/34/58).

71. The United Nations, including all its programmes, funds and specialized agencies, should increase the awareness and expertise of its staff on the right to health of persons with disabilities in order to be able to cooperate more effectively with States from a human rights-based approach. The World Health Organization, as the leading agency in global public health, must include the rights and needs of persons with disabilities in all its lines of work and operations and ensure that the health of persons with disabilities is addressed comprehensively and from a rights perspective, always in close consultation with representative organizations of persons with disabilities.

VI. Conclusions and recommendations

72. **Persons with disabilities have the right to the highest attainable standard of health without discrimination. However, in practice they experience poorer**

access to health care and poorer health outcomes than the general population owing to several structural factors, such as stigma and stereotypes, discriminatory legislation and policies, barriers to accessing primary and secondary care, limited availability of disability-specific services and programmes, poverty and social exclusion. Furthermore, persons with disabilities face serious human rights violations in health-care settings, including denial of treatment; non-respect of their free and informed consent; different forms of exploitation, violence and abuse; and forced sterilization, forced contraception and other violations of their sexual and reproductive health and rights.

73. Mainstreaming the rights and needs of persons with disabilities in health care is crucial to end this situation of inequality. While disability-specific services and programmes are needed to address some of the particular needs of persons with disabilities that cannot be met by making general health care programmes inclusive, as a general rule all health-care services and programmes must be inclusive of and accessible to persons with disabilities. In the framework of the 2030 Agenda for Sustainable Development, States should conduct a review of their national health-care systems with a view to achieving universal health coverage as a way to increase the access of persons with disabilities to health care, particularly primary care services.

74. The Special Rapporteur makes the following recommendations to States with the aim of assisting them in realizing the right to the highest attainable standard of health of persons with disabilities:

(a) Recognize by law the right of persons with disabilities to the highest attainable standard of health and remove all legal barriers that prevent them from accessing health and health-care-related information, goods and services, including legislation that discriminates against them in the provision of health insurance;

(b) Conduct a comprehensive legislative review process to abolish or revoke all laws and regulations that infringe on the autonomy of persons with disabilities receiving health care, including legislation that allows coercion in health-care settings;

(c) Implement inclusive health-care systems that mainstream the rights and needs of persons with disabilities in all health services and programmes, including primary care; and ensure access to specific services and programmes for disability-related needs;

(d) Take appropriate steps to achieve universal health coverage for persons with disabilities and ensure that health-care services and programmes are available, accessible, adequate and affordable for all persons with disabilities;

(e) Guarantee that health-care services and programmes include a human rights-based approach to disability, are non-discriminatory, seek informed consent prior to any medical treatment, respect privacy and are free from torture or other cruel, inhuman or degrading treatment;

(f) Design and implement health literacy programmes and activities that are inclusive of and accessible for persons with disabilities;

(g) Promote early identification and intervention strategies and provide support to families of children with disabilities, including through information, education and services, to increase their understanding and capacities to address the health needs of their children without stigma or discrimination;

(h) Design awareness-raising campaigns and training programmes for health-care professionals to change their perceptions regarding persons with disabilities, and provide guidance on how to render adequate age-, gender- and disability-sensitive services;

(i) Ensure effective and independent monitoring of all public and private health-care facilities and programmes that provide services to persons with disabilities to prevent all forms of exploitation, violence and abuse;

(j) Actively involve and consult with persons with disabilities and their representative organizations in all decision-making processes related to the implementation of health and health-care-related legislation, policies and programmes;

(k) Collect appropriate information, including statistical and research data disaggregated by sex, age and disability, on the health status and the access to health care of persons with disabilities;

(l) Mobilize resources in the framework of the Sustainable Development Goals to increase the access of persons with disabilities to health care, ensuring that all investments are inclusive of them, and refrain from adopting any retrogressive measures that directly or indirectly affects persons with disabilities.

75. **The Special Rapporteur also recommends that the World Health Organization and the rest of the United Nations system adequately consider the right of persons with disabilities to the highest attainable standard of health in all their work and operations, in close consultation with representative organizations of persons with disabilities, including when assisting States in achieving universal health-care coverage and in the implementation of the Sustainable Development Goals.**